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Factors Impacting Questionnaire Response in a Dutch Retrospective Cohort Study

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PURPOSE: To study questionnaire length, type of consent, approach to recruitment, and subject characteristics on participation in epidemiologic studies.
METHODS: As part of a health survey among Dutch subjects treated for ear, nose, and throat disorders in childhood, we conducted a pilot study of 200 individuals who were randomly assigned to one of four categories, defined by length of questionnaire (long vs. short) and type of consent form (basic vs. multi-option). In addition, among 8402 subjects eligible to be in the main study (average age 41 years in 1997), we examined the effect of approach to recruitment and subject characteristics on participation rates.
RESULTS: The pilot study showed a non-significant 10% increase in participation rate using the shorter questionnaire, but no differences by type of consent form. In the full survey, the participation rate was 49% after the first mailing. Response increased by 15% after a written reminder and by 10% after a telephone survey. The total participation rate was 74%. Attained age, sex, exposure status, age at exposure, and response to an earlier survey were determinants of participation rates. Among male non-participants, outright refusal was less frequent than non-response. The refusal rate, unlike the non-response rate, was positively associated with older age at time of survey.
CONCLUSION: Health survey participation is influenced by questionnaire length, frequency of contact, and subject characteristics.
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KEY WORDS: Questionnaires, Epidemiologic Methods, Response Rates, Cohort Studies.

INTRODUCTION

Self-administered mailed questionnaires are widely used in observational studies with a wide variety of study designs, goals, exposures, outcomes of interest, and study population characteristics (1–12). A comprehensive systematic review of available randomized trials from any relevant discipline (not restricted to medicine or epidemiology), identified questionnaire length, use of incentives, appearance of the package, lay-out of the questionnaire, type of follow-up, and registered delivery as most influential factors in terms of participation rates (13). Others have argued that the quality of participants' answers deserves attention as well (14) because clarity and ease of administration may off-set the benefit of a shorter questionnaire, in particular if complex exposures are being assessed (15).

We used a survey as part of a retrospective cohort study on long-term health effects among adult subjects treated for ear, nose, and throat (ENT) conditions in childhood. Because the majority of subjects were treated in childhood, and time since treatment was over 50 years for some, we were concerned that patients not aware of any treatments in the past would be less motivated to participate in the study. In addition, the study protocol involved three elements that could be perceived as threatening to patient privacy. Because a typical informed consent form offers only full participation or complete refusal, we were concerned that a considerable, though unknown, proportion of eligible cohort members would decide against participation because of objections against one but not all aspects of the protocol. We considered questionnaire length and type of consent form to be potentially influential factors in determining the participation rate.

In response to earlier recommendations (6, 16), we report on a pilot study that compared participation rates for a health questionnaire survey among cohort members randomly assigned with respect to questionnaire length and type of informed consent. Subsequently, in the full cohort we examined the effects on participation rates of study

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Selected Abbreviations and Acronyms

CI = confidence interval
ENT = ear, nose, and throat
NRI = nasopharyngeal radium irradiation
OR = odds ratio

population characteristics and the contribution of successive non-responder approach strategies.

MATERIALS AND METHODS

Study Population

We studied the long-term effects on health of nasopharyngeal radium irradiation (NRI) in a nationwide cohort of Dutch patients treated for ENT conditions between 1945 and 1981 (17, 18). We identified 5,358 eligible patients ever treated with NRI and a frequency-matched comparison group of 5,265 subjects who had also been treated for ENT conditions, but had never been exposed to NRI. Half of the cohort had received a questionnaire in 1985, 12 years before the present study (19, 20). The median age at treatment was 6 years and the median follow-up time was 30 years.

Randomized Pilot Study

We compared participation rates for an 8-page, 33-item "short" questionnaire covering basic characteristics, health status, and exposure to carcinogens other than NRI with a "long", 12-page, 54-item questionnaire, containing additional questions on female reproductive history, occupational exposures, and diet. In addition, we compared a consent form with a single signature and date at the bottom with a "multi-option" consent form which differed only in that the subjects were provided choices with regard to participation in three phases of the overall study. The three study procedures requiring individual informed consent were: 1) retrieval of medical data from ENT files; 2) retrospective and prospective linkage with The Netherlands Cancer Registry; and 3) keeping study files for 20 years at the coordinating research center.

A random sample of 200 subjects was selected from one clinic which contributed 65% of the cohort. Subjects were randomly assigned to one of four groups, treated as follows: a) short questionnaire, standard consent form; b) short questionnaire, multi-option consent form; c) long questionnaire, standard consent form and d) long questionnaire, multi-option consent form. The pilot survey included a first mailing and a written reminder after 4 weeks among non-responders. Both mailings consisted of a personal invitation letter, a questionnaire (short or long), a consent form (basic or multi-option) and a pre-paid return envelope. Refusers were instructed to return the blank consent form. The reminder letter mentioned the possibility of telephone contact in case of no response. Within 4 to 8 weeks after the second mailing, a concerted effort was made to contact non-responders by telephone, as needed, at different times of a day during different days of the week (including Saturdays). At least 10 contact attempts were made. For all non-responding subjects who had not been reached by phone, a home visit was planned, preceded by a letter offering the explicit possibility of refusal. If the refusal note was not returned within 10 days, three attempts were made for a home visit.

Questionnaire Survey in Full Cohort

Based on the results of the randomized pilot study, a final questionnaire (8 pages, 43 items) and informed consent document (basic type) were used. The approach strategy was analogous to the pilot study, but home visits were omitted.

Analytic Cohort

Of the total cohort (N = 10,623), 86% were known to be alive, 6% had died and 8% were lost to follow-up. Of 9,142 subjects known to be alive and residing in the Netherlands, 740 subjects were excluded from the present analyses because they were not eligible for all approach procedures, i.e., a second mailing or attempted contact by phone. The first mailing revealed that this group of subjects had moved recently. Although they all eventually received at least one questionnaire by mail, we were not able to conduct the whole cycle of two mailings and a telephone survey for this group because tracing efforts were not completed in time. Thus, the analyses on determinants of participation rates included 8,402 subjects.

Statistical Methods

Chi-square tests were used to test for differences in participation rates in the randomized pilot study (21). In the full-study analysis, the association between response level (participant, non-responder, or refuser) and a particular explanatory variable (male or female, exposed or non-exposed, age at treatment, attained age, previously studied or not, and clinic where treated) was evaluated by orthogonal decomposition of Chi-square for independence of the row and column variables in a general 2-way contingency table, as approximated by Poisson model linear logistic regression using the AMFIT algorithm (22). In the model, the rows and columns correspond to levels of two categorical variables, and the interaction is evaluated as the residual deviance after adjustment for row and column main effects. This deviance, with degrees of freedom $2 = (3 - 1) \times (2 - 1)$ or $8 = (3 - 1) \times (5 - 1)$, depending upon the explanatory variable, was decomposed

into the interaction between the explanatory variable and the contrast between participants and non-participants, with 1 or 4 degrees of freedom, depending upon the explanatory variable, and the residual, again with 1 or 4 degrees of freedom, representing interaction with the contrast between non-responders and refusers. For the two age variables, trend tests were based on single-degree-of-freedom contrasts based on the product of the age as a continuous variable and each of the two response contrasts. A multivariate logistic regression analysis was performed to quantify the association of each of the selected variables with the participation rate, adjusting for the effects of other variables. Forward stepwise confounder selection, in which the effect of adding one confounder at a time is evaluated, was based on a likelihood ratio test (23). A 5% α-level was applied for statistical significance and confounder selection.

RESULTS

Randomized Pilot Study

Age-, sex- and exposure-category distributions were similar among the four randomized groups. Overall, 144 out of 200 (72%) questionnaires were completed (Table 1). Short questionnaires were more frequently completed (77%) than long questionnaires (67%), but the difference was not statistically significant (95% CI, −2, 22). Refusal rates were comparable but non-response rates were lower for short questionnaires (7%) than for long questionnaires (15%) (results not shown in table). The participation rates by type of consent form were comparable, but the refusal rate was slightly higher among subjects who received the multi-option consent form (20%) compared with the basic form (14%)(results not shown in table). Of 71 participants in the multi-option consent subgroup, 65 (92%) gave full consent and three gave partial consent, i.e., permitted two out of three study procedures. The other three subjects had not completed the form correctly. Furthermore, the pilot study showed that home visits added only two percentage points to the overall participation rate. Based on these findings, we decided to use a shortened questionnaire and a basic consent form in the final questionnaire survey, and to omit the home visits from the approach strategy.

TABLE 1. Participation rates (%) by type of questionnaire and consent form. A randomized pilot study in the Netherlands NRI cohort study (n = 200)

	Questionnaire		
Consent Form	Short	Long	Overall
Basic	78	68	73
Multi-option	76	66	71
Overall	77	67*	72

*Different by questionnaire length 10% (95% CI, −2% to 22%), p = 0.12.

Questionnaire Survey in Full Cohort

Of 8,402 eligible subjects, 6,235 (74%) completed a questionnaire. For subjects who were non-responders after 2 mailings (n = 2202), we traced telephone numbers for 1,649 (75%); 835 among them participated by phone, thus increasing the total participation rate by 10 percentage points (Table 2). The contribution of the telephone survey showed an inverse trend with attained age (i.e., age in 1997), and was most effective among subjects younger than 30 years of age at time of questionnaire completion (adding 13 percentage points), and much less among subjects older than 70 years (adding 5 percentage points) (Table 3). Other variables that showed statistically significant variation in effectiveness of the telephone survey were sex and clinic. In crude analyses, the absolute overall participation rate was higher in women vs. men, exposed vs. non-exposed, and younger (<60 yrs) vs. older (⩾60 yrs) subjects (Table 3); exposed females had the highest participation rate (81%) and non-exposed males the lowest (69%). Subjects treated between 3 and 15 years of age had higher overall participation rates than those treated at younger or older ages. However, the majority of subjects over 15 years of age at treatment were also 70 years or older in 1997 so this finding might be attributable to attained age.

TABLE 2. Contribution of subsequent approach procedures to the participation rate and the refusal rate in the Netherlands NRI full cohort (N = 8,402) questionnaire survey

	Mailing 1		Mailing 2		Telephone Survey		Total*	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Participation	4,137	(49%)	1,257	(15%)	835	(10%)	6,235	(74%)*
Refusal	273	(3%)	520	(6%)	446	(5%)	1,246	(15%)‡*
Reached, no response†					247			
Not reached					39		921	(11%)
Not called					82			
No phone number¶					553			

*Totals includes 13 subjects from home visit phase of the pilot study: N = 6 participated and N = 7 refused.
‡Percentage does not add up to total refusal rate due to rounding.
†Preferred not to complete survey over the phone – committed to complete and send in questionnaire, but failed to do so.
¶25% of those eligible for the telephone survey (N = 2202) were either not listed in public available resources or did not have a telephone company contract.

TABLE 3. Contribution of mailings and telephone survey to overall participation rates in the Netherlands NRI (full cohort) questionnaire survey, by population characteristics

Characteristic	No.	Participation rate (%)		
		After two mailings	Additional, from telephone survey	Total[†]
Sex				
Female	3701	68	9	77
Male	4701	61	11	72
P (χ^2 *test)*		*	*	*
Exposure status				
Non-exposed	4123	60	11	71
Exposed	4279	68	9	77
P (χ^2 *test)*		*		*
Attained age (yrs)				
<30	1361	61	13	74
30–39	2653	65	11	75
40–59	3806	66	9	75
60–69	338	60	8	68
⩾70	132	54	5	59
P (χ^2 *test)*		*	*	*
Age at treatment (yrs)				
<3	1102	59	12	70
3–4	1602	67	9	76
5–9	3565	66	11	77
10–14	1041	64	10	74
⩾15	1092	60	8	68
P (χ^2 *test)*		*		*
Time since treatment (yrs)				
<25	1863	63	12	74
25–29	1625	64	11	74
30–34	1458	64	10	74
35–39	1684	66	9	75
⩾40	1772	65	8	73
P (χ^2 *test)*				
Included in previous (1985) questionnaire survey?				
Yes	3886	66	9	75
No	4516	63	11	74
P (χ^2 *test)*				
Clinic[‡]				
1	5991	64	10	75
2	831	63	15	78
3	1138	67	5	71
4	195	59	8	67
6	247	64	6	70
P (χ^2 *test)*			*	*

*P (χ^2 test) <0.001.
[†]Percentages do not always add up to total participation rate due to rounding and because participants (N = 6) after home visit (as part of the pilot study) are only counted in total participation rate.
[‡]Due to exclusion of 4 clinics (see *Methods section*) clinic numbers are not sequential.

Next to differences by approach strategy, we were also interested in differences between refusers and non-responders with regard to study population characteristics. The right-hand columns of Table 4 show results of univariate statistical tests for participants vs. non-participants, and for non-responders vs. refusers. Several characteristics were differently distributed between refusers and non-responders. A clear picture of declining participation rates and increasing refusal rates with older attained age emerged. Males had higher non-response rates than females, but comparable refusal rates. Although exposed subjects were more likely to participate than non-exposed subjects, there was no significant difference in the distribution of exposure status among the non-participants.

The multivariable assessment of participation rates by population characteristics (Table 5) generally confirmed the results of the crude analyses: Women and exposed subjects were more likely to participate than their respective counterparts—men and non-exposed subjects. Furthermore, there was a trend of decreasing participation probability with increasing attained age. Also, participation rates decreased with increasing age at treatment, with the exception of those who were treated as infants or toddlers (<3 years). In contrast to the results in Table 3, subjects *not* included in the 1985 survey were more likely to participate in the current survey compared with subjects who had already been contacted in 1985 after adjustment for other factors of interest. Similar analyses were performed for non-responders (compared to participants + refusers) and refusers (compared to non-responders + participants), with results comparable to the patterns described in Table 4, i.e., a trend of increasing refusal rates with increasing attained age and a tendency for male non-participants not to respond.

DISCUSSION

In a randomized study among 200 subjects we found a difference in participation rate according to questionnaire length (10%). Although not statistically significant, the difference was judged large enough for us to use a short questionnaire in the final questionnaire survey. Interestingly, findings of a recent systematic review of 292 randomized studies also predicted that use of a short questionnaire would add approximately 10% to the absolute participation rate, given a baseline rate of 70% for a longer version [13]. The use of a multi-option type of informed consent form vs. a basic form did not affect participation rates. The multi-option consent form was conceived to offer the possibility of partial consent to cohort members with strong views regarding the privacy surrounding their medical history and future medical conditions. Nevertheless, this option was chosen by only six participants of the subgroup (N = 100) to whom we offered the possibility of partial consent. Three of them had misunderstood the form and their data could not be used for the study. Based on limited use of the multiple options, we decided to use a basic type of consent form in the final survey. Despite the small sample, the results of the randomized study provide insight into the effects of questionnaire length and type of consent form in a population exposed

TABLE 4. Description of three questionnaire response subgroups by cohort characteristics

	Questionnaire response subgroups*			Univariate statistical tests#			
		Non-participants		Participants versus non-participants		Non-responders versus refusers‡	
Characteristic	Participants N (%)	Non-responders N (%)	Refusers N (%)	Chi-square	df	Chi-square	df
Sex				29.18¶	1	11.05¶	1
Female	2,854 (77)	322 (9)	525 (14)				
Male	3,381 (72)	599 (13)	721 (15)				
Exposure status				38.02¶	1	0.54	1
Non-exposed	2,936 (71)	496 (12)	691 (17)				
Exposed	3,299 (77)	425 (10)	555 (13)				
Attained age (yrs)				36.75¶	4	119.79¶	4
<30	1,010 (74)	215 (16)	136 (10)				
30–39	2,001 (75)	301 (11)	351 (13)				
40–59	2,848 (75)	362 (9)	596 (16)				
60–69	231 (68)	25 (7)	82 (24)				
⩾70	145 (59)	18 (7)	81 (33)				
Age at treatment (yrs)				47.07¶	4	79.55¶	4
<3	775 (70)	168 (15)	159 (14)				
3–4	1,224 (76)	182 (11)	196 (12)				
5–9	2,730 (77)	381 (11)	454 (13)				
10–14	766 (74)	103 (10)	172 (17)				
⩾15	740 (68)	87 (8)	265 (24)				
Included in previous (1985) questionnaire survey?				2.44	1	9.67¶	1
Yes	2,915 (75)	377 (10)	594 (15)				
No	3,320 (74)	544 (12)	652 (14)				
Clinic†				19.70¶	4	17.95¶	4
1	4,471 (75)	687 (11)	833 (14)				
2	649 (78)	63 (8)	119 (14)				
3	812 (71)	116 (10)	210 (18)				
4	131 (67)	29 (15)	35 (18)				
6	172 (70)	26 (11)	49 (20)				

N: Number of subjects; Exp: expected number of subjects from contingency table analyses; df: degrees of freedom.
*Percentages do not always add up to a hundred due to rounding.
†Due to exclusion of 4 clinics (see *Methods* section) clinic numbers are not sequential.
‡Adjusted for participants.
#See Materials and Methods for details.
¶$P < 0.05$.

to medical treatments in (early) childhood, after a follow-up of several decades. We are not aware of other reports that compare different consent forms in a mailed questionnaire survey.

The full questionnaire survey among 8,402 subjects resulted in a final participation rate of 74%, which is 10 to 15 percent lower than rates observed both in the previous follow-up of part of this cohort (19) and in a similar US-based survey conducted in 1980 among 3,000 subjects treated at an ENT clinic in childhood (24). Yeh et al. (25) recently reported on prolonged follow-up of the US cohort, with a participation rate of 90% among subjects who had responded to a 1978 questionnaire. An analysis that we did that was limited to participants in the 1985 survey showed a lower participation rate (77%) compared with the US cohort. Among other US cohorts of subjects irradiated in childhood or young adulthood (26, 27) conducted before 1990, questionnaire survey participation rates well above 80% were also reported . The US-cohorts (25–27) were based on single hospitals that conducted their own follow-up studies, whereas our study included subjects from several facilities, with an external coordinating center. This might have contributed to the lower participation rate in our study. Despite concern about declining willingness to participate in epidemiologic surveys (16), a recent review showed that participation rates among controls in case-control studies were only moderately associated with calendar year of study, after adjustment for effects of study location and type of disease studied (28).

Analysis of the separate contributions of successive approach strategies revealed that both the reminder mailing and the telephone survey contributed substantially to final participation rates, particularly in the younger age groups. The telephone survey was particularly useful for explaining study procedures, and for providing information on the NRI treatment for subjects who were unaware of their past ENT

TABLE 5. Multivariate analysis of cohort characteristics associated with the overall participation rate in the Netherlands NRI (full cohort) questionnaire survey

Characteristic	OR of participation* (95% CI)†
Sex	
Female	1.0‡
Male	0.8 (0.7 to 0.8)
Exposure status	
Non-exposed	1.0‡
Exposed	1.3 (1.2 to 1.5)
Attained age (yrs)	
<30	1.0‡
30–39	1.0 (0.9 to 1.2)
40–59	1.0 (0.8 to 1.2)
60–69	0.9 (0.6 to 1.3)
⩾70	0.6 (0.4 to 0.9)
Age at treatment (yrs)	
<3	1.0‡
3–4	1.3 (1.1 to 1.5)
5–9	1.2 (1.1 to 1.5)
10–14	1.1 (0.9 to 1.3)
⩾15	1.0 (0.8 to 1.3)
Included in previous (1985) questionnaire survey?	
Yes	1.0‡
No	1.2 (1.0 to 1.4)
Clinic§	
1	1.0‡
2	1.1 (0.9 to 1.3)
3	0.8 (0.6 to 0.9)
4	0.7 (0.5 to 0.9)
6	0.8 (0.6 to 1.1)

*Participants versus non-participants (=non-responders + refusers).
†OR = odds ratio; CI = confidence interval; from a logistic regression model.
‡Reference category; §due to exclusion of 4 clinics (see *Methods* section) clinic numbers are not sequential.

treatment. Additional home visits did not contribute further, as was also reported in a meta-analysis of German case-control studies (29). In agreement with several other studies on the late health effects of childhood radiation exposures (24, 27, 30) we found a statistically significantly lower participation rate among non-exposed subjects. Higher participation rates among females and younger subjects have been reported in some, but not all studies (3, 6, 12, 31), and may depend on age-distribution, research topic, and number of attempts to contact non-responders.

Strengths of the study include the availability of individual medical records with accurate information on personal identifiers, and of municipal registry-based follow-up, thus ensuring a very high probability of contacting the correct individual at the correct address.

In summary, we reported on characteristics of participation in a retrospective cohort study of subjects treated for ear, nose, and throat conditions in childhood. Questionnaire length appeared to be a determinant of the participation rate, whereas offering the option of separate consent to medical data retrieval, cancer registry linkage, and long-term storage of individual medical data was exercised by only a small proportion of participants. A reminder mailing and a telephone survey added substantially to the final participation rate, whereas additional home visits did not. Attained age, sex, exposure status, age at treatment, and having participated in a former follow-up were determinants of participation rates.

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